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## Integrating self-management into daily life following primary treatment: head and neck cancer survivors' perspectives

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### Abstract

**Background:** Self-management may help cancer survivors to better deal with challenges to their physical, functional, social, and psychological wellbeing presented by cancer and its treatment. Nonetheless, little is known about how people integrate cancer self-management practices into their daily lives. The aim of this study was to describe and characterise the processes through which head and neck cancer (HNC) survivors attempt to integrate self-management into their daily lives following primary treatment.

**Methods:** Using a purposeful critical case sampling method, 27 HNC survivors were identified through four designated cancer centres in Ireland and participated in face-to-face semi-structured interviews. Interviews were audio-recorded, transcribed and analysed using thematic analysis.

**Results:** Six themes describing HNC survivors' attempts to integrate self-management into their lives following treatment were identified: *grappling with having to self-manage, trying out self-management strategies, becoming an expert self-manager, struggling to integrate self-management strategies into daily life, avoiding recommended self-management and interpreting self-management.*

**Conclusions:** This is the first study to describe HNC survivors' attempts to integrate self-management into their daily lives following primary treatment. The findings indicate that HNC survivors exhibit highly individualised approaches to self-management integration and abandon self-management strategies that fail to meet their own specific needs.

**Implications for Survivors:** Survivors may benefit from skills training and structured support to assist their transition between in-patient care and having to self-manage after primary treatment, and/or ongoing support to deal with persistent and recurring challenges such as eating difficulties and fear of recurrence.

**Keywords:** head and neck cancer, cancer survivorship, self-management, qualitative, psycho-oncology.

Substantial progress in cancer detection, diagnosis and treatment means that many people are living longer with the consequences of cancer and its treatment [1]. However, while cancer patients often receive a lot of in-patient support, there are limited health service resources available once primary treatment has ended [2]. Furthermore, in this post-treatment period, the consequences of cancer and its treatment carry a significant physical, emotional and social burden for survivors [3-4]. These factors amplify the importance of the individual survivor's role in the self-management of their condition and its treatment consequences following primary treatment [2-7]. Cancer self-management may be defined as “awareness and active participation by the person in their recovery, recuperation and rehabilitation, to minimise the consequences of treatment, and promote survival, health and well-being” [8, p.6]. Following primary treatment, this can involve active monitoring for signs of recurrence [9], managing emotional distress [10], returning to normal roles and routines [4], effectively collaborating with health-care providers [5] and adjusting to late effects of cancer and its treatment [4].

Although the importance of active self-management is often emphasised in the literature, there is a dearth of research investigating how people integrate self-management practices into their daily lives following cancer treatment. Such research is important as it may help to identify how some people successfully integrate self-management into their daily lives, while others do not. Relatively limited research has considered how self-management becomes integrated in the lives of individuals with long-term illnesses generally [e.g. 11-14]. This research may not explicitly relate to cancer, as it has been recognised that self-management practices may vary in importance depending on specific issues associated with the illness itself [15], and that cancer self-management, in particular, may vary depending on cancer type, treatment type and stage of the illness trajectory [16]. Furthermore, research has demonstrated that cancer itself is perceived to be associated with significant existential and emotional threat, above and beyond that associated with other long-term illnesses [1;17], which may mean that the process of attempting to integrate self-management into daily life is qualitatively different for cancer survivors.

The current research was designed to understand the process of how head and neck cancer [HNC] survivors attempt to integrate self-management into their daily lives following primary treatment. In the post-treatment period, HNC survivors encounter a range of challenges associated with HNC and its treatment which require ongoing self-management, such as eating and speech difficulties [18], facial disfigurement [19], fear of recurrence [20] and elevated distress levels [21]. Because of the ongoing need for HNC survivors to self-manage these challenges, they are a particularly appropriate patient group to research in relation to their attempts to integrate self-management into their daily lives. Our recent research has described the wide variety of strategies that HNC survivors employ to self-manage these challenges [22] and the barriers to self-management [23] following primary treatment. The aim of the current paper is to describe and characterise the processes through which HNC survivors attempt to integrate self-management into their daily lives following primary treatment. This information could inform health care providers and intervention developers on how best to support HNC survivors to self-manage.

## **Materials and methods**

### **Study design**

The study used a qualitative methodology with semi-structured interviews to capture HNC survivors' experiences of the processes of attempting to integrate self-management into their daily lives following primary treatment.

### **Participants and recruitment process**

Following ethical approval, Clinical Nurse Specialists (CNSs) from four designated cancer centres in Ireland helped with study recruitment. We employed a purposeful critical case sampling approach [24] where each CNS was asked to identify HNC survivors with particular functional and psychosocial challenges (speech difficulties, swallowing difficulties, facial disfigurement or social isolation) for potential inclusion in the study. These functional and psychosocial challenges had been identified as critical challenges in HNC survivorship requiring ongoing self-management, following consultation with an expert advisory group consisting of experienced HNC researchers and clinicians. Eligible individuals had experienced at least one of these challenges in the post-treatment period, were 8-60 months post-diagnosis, were at least 18 years old and spoke sufficient English. Individuals were not eligible to participate if they were undergoing or awaiting treatment for HNC, or if they were receiving end-of-life care. Using these criteria, CNSs sent eligible individuals a study pack, which included a letter of invitation, information sheet, reply slip and pre-paid envelope addressed to the first author. Upon receipt of a reply slip, the first author contacted those interested to arrange an interview at a time and location that was suitable to them. Following this process, 27 individuals were interviewed by the first author (for full sample characteristics, see [22]).

### **Data collection and analysis**

All participants read a plain language statement and signed an informed consent form before the interview started. The interviews were semi-structured around a topic guide, which included a series of open-ended questions about how participants managed condition-related challenges they had encountered following HNC treatment. Each interview was audio-recorded (with the participant's consent) and the data were subsequently transcribed verbatim and anonymised.

The data were thematically analysed for material relating to the processes involved in HNC survivors' attempts to integrate self-management into their daily lives following primary treatment. The analysis used an inductive thematic analysis approach outlined by Braun and Clarke [25]. We adopted an inductive thematic analysis approach (rather than employing a deductive approach based on a pre-existing conceptual framework) due to the dearth of research on this topic in relation to HNC; this allowed us to document the processes of self-management integration in a bottom-up fashion in a manner which was sensitive to the specific context of HNC survivorship. Following data immersion, the first author coded pertinent features of the data relevant to the study aim, reviewed these codes in order to purposefully identify themes and subsequently related this thematic material back to coded data extracts to ensure it was sensible and coherent; any themes which did not fit well with the data or did not have enough associated data were discarded at

this stage. The resultant themes were then clearly defined and named. Finally, in light of the inter-relationship between certain themes, the first author constructed a tentative model which illustrates a potential sequential process of self-management integration in HNC survivorship, over-arching themes of importance to self-management integration and themes relating to difficulties that participants experiences in their HNC self-management integration. The credibility and trustworthiness of this analysis process was enhanced by the final author cross-checking the quotes and themes throughout the analysis process. Quotes from participants are provided to illustrate the themes; these participants have been allocated a pseudonym (of the same sex) to protect their identity.

## Results

The six themes presented below describe key aspects of HNC survivors' attempts to integrate self-management into their daily lives following primary treatment. The first three themes describe specific processes of self-management integration, specifically *grappling with having to self-manage*, *trying out self-management strategies* and *becoming an expert self-manager*. Some participants found it difficult to integrate self-management into their daily lives following primary HNC treatment, and the fourth and fifth themes describe specific processes relating to their difficulties with self-management integration: *struggling to integrate self-management strategies into daily life* and *avoiding recommended self-management*. The final theme *interpreting self-management* describes two over-arching perspectives, which HNC survivors adopted once they had begun to actively engage with the process of self-management integration: *focusing on recovery* or *focusing on everyday life*. Figure 1 illustrates the potential inter-relationship between these six themes. As indicated in this diagram, participants often experienced the processes of *grappling with having to self-manage*, *trying out self-management strategies* and *becoming an expert self-manager* sequentially; however, it should be emphasized that, in many cases, these processes occurred simultaneously, or overlapped with each other. Furthermore, as per the diagram, *interpreting self-management* occurred at all stages of this potential sequential process, while difficulties relating to self-management integration (i.e. *struggling to integrate self-management strategies into daily life* and *avoiding recommended self-management*) could occur at any stage of the sequential process, and appeared to interfere with this process for the HNC survivors who experienced such difficulties.

[Insert Figure 1 here]

### Grappling with having to self-manage

HNC survivors described how they grappled with having to self-manage their condition initially following primary treatment. Grappling involved initial attempts to “grab hold of” self-management practices and incorporate them into daily life, a process characterized by difficulty and internal conflict. In this initial post-treatment period, survivors faced a range of problems they had to self-manage as they moved away from the structured support of their multidisciplinary team. Indeed, the short-term consequences of HNC treatment can be quite problematic as they often require intensive medical self-management. For instance, Timothy, who was restricted to PEG tube feeding following treatment, described the difficulties in his attempts to feed himself and maintain a healthy

weight. In particular, he experienced a conflict between his body and mind in relation to maintaining this practice; a simultaneous disinterest and obsession with food.

[I had] just a total absence, disinterest in food. However, at the same time, [I had] unhealthy dreams with an obsession about food and an obsession with watching cookery programmes. My body was telling me, “You want food”, but my mind was telling me the other way, no interest. Well, my body and my weight were just going down slowly. But I was being kept alive with liquid foods. And the chore of, in the morning, having to pump water through your [PEG] tube and then food and then medication, and cleaning it with water again. And a few times at night the tube leaked, and you would wake up with a pool of smelly liquid on the sheet under you. And your little machine with your bag of food, feeding you during the night... it’s not very appetizing, I suppose. And you gradually lose the interest in food. [Timothy, 57 years]

Moving away from the structured support of the multi-disciplinary team also affected HNC survivors’ emotional balance in the period following treatment. Eimear described how she grappled with having to self-manage in this period; she experienced a sense of conflict between wanting to return to the security of the hospital and wanting to stay at home to self-manage her condition independently.

I went down [emotionally] when I came out of hospital. The worst time was the month I came out of hospital. It felt like I’d no support system because the doctors and nurses weren’t around me all the time. And when I went back to see them about two weeks after the hospital, they said, “How are you?” And I just cried, and cried, and cried. [Laughter] They couldn’t get any sense out of me. After about ten minutes, I was hoping they would take me back in, and then I was hoping they wouldn’t; because I wanted the security of being back in the hospital, but I didn’t want to go back in. [Eimear, 56 years]

Difficulties managing emotions also manifested for participants in other ways in this initial period following treatment. Ronan characterized this period in terms of frustration when faced with an inability to do things he was previously able to do; in this case he highlighted an impulse to lash out at others, which he had to wrestle to overcome.

When I came home from hospital at first, I was a bit peevish. Small things would annoy you. I’d say [for] around three or four weeks, you’d try and do something you couldn’t, and then you were annoyed and you were blaming everyone. It’s no one’s fault but your own. You have to call yourself aside and say, “Here now, this is a bad way to be”. [Ronan, 73 years]

HNC survivors also had to grapple with managing fears of recurrence during the initial post-treatment period. Catherine described how she felt every new sensation in her neck was an indication that her cancer was back.

At the start, I [worried about recurrence]. I kept thinking – every lump in my mouth, every infection I got, or, you know, if it was sore or, like even now if I get– which would be a small thing to a normal person– but you know the little nicks you get? You know, maybe you bit your tongue or it’s just a little boil or something, every single time you get one of them, you think “This is it. This is how it started the last time” [Catherine, 33 years]

HNC survivors also grappled with having to negotiate their self-image and identity in the face of others’ responses to them following treatment. This often initially involved reactive self-management attempts to avoid feeling self-conscious about visible differences. In this context, Adrian described how he oscillated between provoking people to react to his appearance and hiding away from them in

an attempt to gain control over their reactions towards him.

I never really wanted to see anybody, because they would look at you like you were dying, or they didn't know what to say. And you didn't feel as comfortable with them as you did beforehand. So I done a 360 degree thing when my heart fell out. [...] I got a taxi into town and I went to a tattoo parlour and I got my ear pierced, which looked entirely ridiculous for a guy my age. And I got this little hat and wore it back to front and I thought, "I'd rather somebody look at me saying, 'Would you take a look at that idiot trying to be 21,' than look at me and think, 'Oh the poor devil.' I wasn't that bad when I first came home [but] I'd wait till 2 o'clock in the morning and I'd take a wee walk outside the house because I didn't want anybody to see me [and think] "God, he can hardly put one foot in front of the other". And I wouldn't eat with anyone. [Adrian, 56 years]

### **Trying out different self-management strategies**

Most participants engaged in a process of trying out different self-management strategies to investigate whether these strategies were useful in their everyday life. This allowed them to figure out how to manage post-treatment challenges in a way that was most appropriate to their own particular needs through trial-and-error. For instance, Timothy described the process of trying out different foods in the management of his taste changes, which ultimately led him to shift his eating patterns towards food and drink which he would not have chosen in the past.

I [could] taste more the vegetable side, right from the beginning, [rather] than fruit which is acidic [and] it dries out in my mouth. I tried a glass of red wine, which I would have liked, and it tasted like gasoline would. I can drink a glass of beer, because I can taste beer. You learn to shift your patterns in a different direction. You have to make life in some way enjoyable. You can taste some items. So you learn to swing towards those items, and have beer instead of wine. And even though coffee dries out the mouth and I'm advised not to drink it, I can taste it. So I have a little. I always detested porridge. But now I have a whopping great bowl of porridge with honey in the mornings because I can taste it and I look forward to it. [Timothy, 57 years]

This process of trying out self-management strategies also involved survivors re-learning how to perform vital functions in new, and often individualistic, ways that worked for them. In this regard, Rory described how he had to carefully re-learn how to eat and swallow in his own way after initial difficulties engaging in these practices.

The way I can deal with [my eating difficulties] has been to eat and swallow in my own particular way. Every individual is different, so you have to, how would I say it, manipulate yourself or come to terms with how you're going to swallow and so on. It's like a person with a hip placement [sic]; how are you going to walk from now on? It's mind over matter; to teach yourself what to do. In actual fact, it's a teaching process. It's a beginning again of how from now on [you're going to deal with it]. This is the new me now, this is how I'm going to swallow as opposed to how I did swallow. [Rory, 61 years]

The process of trying out different self-management strategies also led participants to abandon strategies they tried and perceived to be less helpful. For instance, Timothy described how he stopped using the internet to seek information when he realised this exacerbated stress and worry about his condition.

One thing I learnt not to do, or stop doing very early on, was my own little research online. Because those websites just frighten the life out of you. Everybody should be warned about them. Especially these websites that people come in and comment. And usually the people who comment are people who are having a rough time, or whose partner maybe had died or was dying, or something. So you see the worst of the situation. And it just panics you. And you learn to stop it. [Timothy, 57 years]

Similarly, Nuala tried a particular medicine in an attempt to manage pain she experienced on the side of her face, but ultimately decided to tolerate pain to avoid medication side-effects.

It had been suggested to me that I take a product called [name removed]. Something to do with the nerves and nerve endings and nerve pain. It's nerve damage, really. I prefer not to take it, because it makes me very drowsy. I couldn't function on it, so I'm better off without it. [Nuala, 62 years]

### **Becoming an expert self-manager**

Once they had tried a range of self-management strategies and identified the ones that integrated well into their life, several HNC survivors described how they learned to become more responsive in their use of these strategies. Becoming an expert self-manager in daily life involved flexible use of different strategies, depending on what they deemed to be most appropriate to meeting their needs in a particular context. For instance, Marcus described how he had learnt to alter his approach to dealing with the phlegm build-up that arose from his laryngectomy stoma depending on whether or not he was in a situation where he had to speak a lot.

I can swallow [the phlegm] now. The only reason I'm not swallowing now is because I'm speaking to you [and] if I swallow that now, it will affect my voice, and it's difficult enough to understand me without me making it more difficult for you. That's why I'm going out to relieve it; because I'm speaking to you. I'll have to get up if I was talking to anybody. I'd have to get up and say, 'Excuse me,' and I may go over to the sink or I may go to the bathroom to spew this out. I get that sometimes, but I can swallow it most of the time. [Marcus, 66 years]

Adrian described how he had developed an ability to respond to fears of recurrence in a way that worked for him depending on the situation; he typically tried to be positive or focus on things other than cancer (such as work) but would engage in self-talk practices to overcome fears when they became particularly strong.

I've never known anybody to get cancer for it not to come back. It's frightening. But if you thought about it 24 hours a day, you'd throw yourself in a river. I just try and say, "Look, you are here and thank God for it." On a particularly bad day, you think, "God, I hope it's not back." I mean, I work. When you are working, you have to concentrate on other things so it's out of your head. I've, kind of, learned to deal with it my own way, I think. But there's always a fear of it coming back. Like, a few days before [a hospital appointment], I would think, "God, I'm up for review, you know, I'm worried about that." [During those times] I, kind of, say the things back to myself that I would like somebody else to say to me. [...] And I try and be positive [in my daily life], and I think I'm as positive as I can be. I go to work. I try not to let it get to me. [Adrian, 56 years]



Timothy also described how he had learnt to become more responsive to managing his fatigue over time, a skill he had initially developed for his working environment before he had gone through HNC treatment. Over time, he learned how to minimize the impact of the added fatigue following treatment.

I've always been one [to] enjoy a little 15 minute power nap at lunchtime. So I find it quite easy to close my eyes and snooze off and visualise something, and then wake up refreshed. So it was just a natural extension of that. But during treatment and for months afterwards, it was a very pronounced nap. I would lie down and off to sleep straightaway. I just couldn't continue on.

Now it's, I feel like having it, I delay it a bit, and then I have a short nap and then I'm off again. [Timothy, 57 years]

Becoming an expert self-manager also involved anticipating challenges that might emerge during a normal day. Nuala described how she had learnt to pre-empt speech challenges she may encounter in group meetings in her working environment by preparing for them in advance or limiting her speech in those contexts.

Whilst I'm fine on a one-to-one basis, if I was speaking in a group, at times, unless I had water with me, my voice can give [way] almost. I'm now very aware that if I'm at a meeting, I'm slow in voicing an opinion on something. When I do, invariably, I keep them to short, clipped sentences. It's just psychologically fearful that my voice would begin to waver or whatever. I'm very conscious of the fact that it can sound weak. If it's a meeting within [work], and if I'm giving a report on something that's happening here, or whatever, prior to the meeting I will have condensed what I want to say. [Nuala, 62 years]

Finally, some participants spoke of becoming expert self-managers through their incorporation of self-management behaviours into their daily routines. For instance, Eimear described how she had learnt to incorporate mouth exercises recommended by a speech and language therapist into her routine by performing them when she drove.

The exercises have to become second nature to you. I do them all the time. My trigger is: I'm driving the car, red traffic lights, I do my exercises. So that's it: brush my teeth, do my exercises; brush my hair, do my exercises; red traffic lights, do my exercises. The exercises are the key. And that's what I mean by the physios and the speech and language: they give you your life back. [Eimear, 56 years]

### **Struggling to integrate self-management strategies into daily life**

Some HNC survivors described how they continued to struggle with their attempts to integrate self-management into their daily lives following treatment. For many of these participants, this struggle related to the context of their lives. One participant described how he had been repeatedly unsuccessful in attempts to give up cigarettes because of triggers that he encountered in his daily life.

[I smoke] 10 to 15 [cigarettes] a day. [Consultant] said, "That's too much." None at all is the answer. I want to [give up]. But it's very hard doing it, so it is. Especially after having a cup of tea, or sandwich, and then the addiction's there straight away after. I've tried everything. Nothing seemed to work. I tried even the chewing gum. Willpower is the only answer. I'll have to do something. I don't know how. If I could stop, surely [I would], because they want me to. [Eoghan, 64 years]

Rory described how he had continued to struggle with self-management of eating and swallowing difficulties after a prolonged period of grappling with his self-management of these difficulties; in particular, he consistently regurgitated his food, which continued to make him embarrassed to eat with others and led him to isolate himself from others.

You will not submit to my company while I'm eating my bit of dinner. Some [food] I can't swallow and I can only get a little bit into me. It's a very hard process. I have to take my time. The rest I have to regurgitate. When you eat into your chest, whatever's in there with your food, it mixes [with phlegm]. I consume as much as I possibly can– the rest I spit out, otherwise it would choke me. And another thing with the regurgitating – It blocks [your nose] and I have to wait for hours until, eventually, it frees it and comes down so I can breathe properly. Can you picture a man sitting down there and eating and next minute [makes hocking noise], right? It's not very nice if you're sitting at a table, is it? That's why I can never go to a wedding or a social [event] and sit down and eat. [...] I want a little bit of dignity back. I didn't break my shoulder or my arm, or indeed my foot and [there's] a little small detail of a hole in the middle of my face. I need to get back some confidence. [...] It has affected my eating, my socializing– which I don't do; I'm here 24/7. Other than going to the shop, bringing my wife to the shop, going to see my GP, any hospital appointments – that's it, end of story. [Rory, 61 years]

Rory also described how he continually struggled to adjust to restricted activity following primary treatment due to increased levels of fatigue, which forced him to retire from his job. He described how this struggle related to difficulties accepting the “new normal” due to aspects of his identity that were related to his working life and the sense of independence he had previously derived from it.

If I do anything now, energetic or excessive, like moving that [chair] from here to there; [if I do that] for one half hour, I have to lie down for four [hours]. I am totally drained. It kills me and it hurts me so much that I'm not able to go to work. That was my life, my independence. I'd go back in the morning if I could. It was my identity, my therapy; a man's life is his work, you know? It's dignity – that's what I call it. And I know I'll never work again and psychologically that can't be good. [Rory, 61 years]

Similarly, Jacinta described how she continued to struggle to accept “the new normal” relating to her speech difficulties. These speech difficulties made her feel like a different person, which continued to frustrate her.

[I'm] a completely different person. I'm getting a little better at not getting so frustrated. But terribly frustrated... If you wanted to explain something, and at that moment you couldn't because of a handicap [speech-related difficulties], that would cause me such anxiety. [...] You're compromised. And straightaway, [that] puts you in a no-win situation. [Jacinta, 71 years]

### **Avoiding recommended self-management**

Rather than struggling with integrating particular recommended self-management strategies, some participants simply avoided them. In some cases, such avoidance related to learned patterns of behavior. Jacinta admitted that she tended to avoid attending appointments with her doctor as she was fearful that they may lead to additional negative revelations about her health status, a pattern of behavior which she may have learned from her mother.

When I was growing up, no one went to hospital unless they were literally on the way out. You never went to doctors either, the old people, my mother's age group, you know? So I probably inherited a bit of that. [...] I don't go to the doctor like I should.

I'm always afraid they'll find something else, and I don't want to hear it, really. [Jacinta, 71 years]

Other participants avoided recommended self-management practices through their continual use of other more negative behaviours as a means of coping with their situation. Colm described how he became over-reliant on alcohol to soothe himself following HNC treatment. This exacerbated issues such as paranoia and communication problems; ultimately, his marriage broke down and he was admitted to a psychiatric institution after an alcohol overdose.

[My wife's] patience wore out with my overuse of alcohol, to just relax myself and just keep myself calm. Without realizing, I was being verbally aggressive, my demeanour, my nature had changed over the last couple of years. I couldn't see the change within myself, but the family could. [I started becoming] less patient with everyone. Verbally aggressive, so I'm told.

Unfortunately, I was the kind of person that couldn't see how badly they were actually being affected by everything. Eventually, just last week, my wife said, "That's enough. I've had enough." We had normal kind of problems before the illness. The drinking didn't help with those problems, paranoia and so on setting in. Every problem seemed to be exacerbated because of overuse of alcohol. The end result was that on Friday two weeks ago I took an overdose with drink and was admitted to [hospital name removed] and just spent the last week in the Psychiatric Evaluation Unit in [hospital name removed]. [Colm, 53 years]

In order to deal with these significant life events, Colm further avoided recommended self-management behaviours by taking up smoking again, which he perceived as a behaviour which helped him to cope.

I'm off the drink, for obvious reasons, but the cigarettes are back for the time being. I had given up. I'd say I'd probably been off them for a year, but I just felt I needed something [to help me cope]. [Colm, 53 years]

Another participant, Cillian, described how he too avoided recommended self-management by engaging in problematic drinking to overcome boredom and frustration at his perceived loss of freedom following treatment. He described his over-use of alcohol during this period as a passive process, where he was "going through the motions", one which he wanted to overcome but which he felt he was not willing to fight against.

The hardest thing to clear up [is] the drink. That's just eating me. It's just keeping the boredom away, that's all; keeping the fucking insanity maybe away too. It's just happening, and that's it, and I'm going through the motions. [...] I think it's the boredom because you didn't bother about drinking [before having gone through the treatment], you could be getting into a car and drive away for the day, or go out for a couple of days if you wanted. That would be a good [alternative] way of coping. If drinking is a way of coping... that's not a way of coping about anything now. Once you've started, that's it, you are done and dusted. You see, I'm in haze at the moment. I'm in a haze of drink. I want to try to prove myself as far as not drinking is concerned. Like, if you can't help yourself, who the hell can help you? You can get all the help in the world, but when you are not willing to do it... You see, I try and drink as much as your body will allow you take, and that's it. [Cillian, 58 years]

## Interpreting self-management

Those participants who had begun the process of self-management integration described different ways in which they interpreted self-management in the specific context of their lives, differentially forming a perspective on self-management which primarily focused on their recovery or their everyday life. In relation to the former, several participants described how they began to recognize the potential for self-management to assist in their recovery at a particular point in time, and that self-management practices were a necessary addition to their daily lives. These participants formed a perspective on self-management where they recognized the potential for self-management strategies to assist in their recovery. In some cases, HNC survivors described becoming motivated to recognize the importance of self-management strategies when told they were free from cancer. For instance, Adrian recounted how “being given the all-clear” inspired him to address emotional difficulties and quit smoking through motivational self-talk.

When I went back, [when it] was like the verdict, [I remember] waiting in that waiting room to see [consultant] for maybe half an hour [and it] felt like forever. And then when I went in and he told me “I can’t see anything down there. I’m happy enough,”- It’s just an indescribable feeling. It’s just pure elation, really. And I guess I started feeling a bit stronger after that; the fact that it was gone and he’d see me in three months. Then I’d go in three months and get the all-clear again, and you feel a bit stronger. You’d make an attempt to talk to yourself when you were feeling bad. You’d say, “Look, this guy has given me the all-clear.” It was like a smoking thing, I’d be saying to myself, “there’s kids dying of cancer every day in the week, they don’t deserve to get cancer, they’ve never smoked, and yet you are using up all these resources by smoking that maybe could be used for those children. Will you cop hold of yourself and stop smoking?” So things like that were the motivators for me. [Adrian, 56 years]

Participants who interpreted self-management in this recovery-oriented fashion described how they prioritised their recovery in their daily lives and integrated self-management practices into their lives in a manner that served this focus on their recovery and recuperation. For instance, Eimear described how focusing on milestones of her recovery was an ongoing priority in her daily life, and that self-management practices such as staying fit, eating well and maintaining positive thinking facilitated her in this prioritisation.

You have to get through the first year, because your chances of recurrence are very high [in that period]. The outcome is never very good if it recurs. So when I got to the first year mark, I was like: ‘I’m at the first year mark.’ Now, I’m looking to the second year mark. My treatment will be two years at the end of October, beginning of November. So I’m very much watching that. I know if I get through another year, my statistics go up. The doctors do their job. My job is to stay fit, eat well, sleep well, be positive. Because, I have to do my job as well as the doctors. I was dying to get on to six-monthly visits with the doctors, because then I know I’m definitely getting better. It’s like another milestone. I have to make the milestones. [Eimear, 56 years]

In contrast, other participants interpreted self-management within the specific context of their lives in a manner which prioritized their return to the roles and routines that characterised their lives before cancer. These participants formed a perspective on self-management for their lives which primarily focused on returning to everyday activities that they valued. One participant, Niamh, described how she had initially interpreted self-management in a recovery-oriented fashion, but consciously moved away from this

interpretation of self-management towards a focus on returning to her normal roles and responsibilities from before her illness once she began to feel better.

I remember decision-making [was something] I couldn't [do] during the illness. I said to my husband, "Do not ask me to sign any serious document, because I haven't the energy to figure out whether it is right or whether it is wrong." [Anything] as regards the household, what people ate for dinner, I didn't want to have the decision. I might have thought it was a nice idea for a while to leave everybody else to be dealing with these things. When you are sick, you do live in a little bubble, because all you're really concerned about is your sickness and getting better and your treatment and getting over it. You don't deal with anything else around you, or at least that's what I did. At some point I said, 'I have to go back to being a mother and a wife,' the house keeper, and then going back to work and doing the duties that my job entailed. That was the final step, going back to work. [That helped me feel like I was] in control, I suppose, or that I was dealing with every decision again. [Niamh, 49 years]

This interpretation of self-management often involved the strategic use of self-management strategies as a means to prioritise returning to valued normal activities. For instance, Dorota described how self-management strategies such as motivational self-talk enabled her to focus on everyday life by keeping fears of recurrence at bay.

My cancer cannot be [a burden] on my life all the time. I need really myself go back to normal. My head, my think[ing], my body, my everything. This mean, [I] don't think so much about the past. Think about the future. Right now I feel [I] don't want to lose the mind. I stopped a lot [of negative] thinking because 'this will be the cancer again', or 'maybe something [will] happen [that will be] bad.' No, I cannot [think like this] because you cannot live normal [that way]. But of course, if I feel something strange, probably I will be worry, like very worry [sic]. But I don't like to think like this way. Because you need to say, "Okay this was past. [I need to] start the new life." It is possible [to do this] of course. [Dorota, 30 years]

Another key aspect of interpreting self-management in this way was focusing on returning to work, which gave participants a project to focus on away from their illness. Adrian described how focusing on work helped him to keep depression at bay by feeling like he was contributing financially to his family.

Getting back to work was a huge thing for me. Because if you are hanging around the house, you've nothing to do but think and you are not socialising. Because my wife was working, my kids were at school, so I was in the house with myself, which leaves you nothing, only time on your hands to think. And generally speaking, when you are not feeling the best, you are not really thinking good things, you know. You've got to push yourself to try and think good things. So I think the biggest thing for anybody who is trying to get over their treatment or cancer would be to say, try and get yourself back to work or try and get working in some way with people just to take your mind off that [and] feel like you are contributing again. [Adrian, 56 years]

## Discussion

To our knowledge, this is the first study to describe and characterize how HNC survivors attempt to integrate self-management into their daily lives following primary treatment. We have identified six key themes in this context. Three of these themes potentially

describe a sequential process of survivors' attempts to integrate self-management into daily life: from initial attempts at *grappling with having to self-manage*, through *trying out self-management strategies* to *becoming an expert self-manager*. While several participants experienced these processes sequentially, it should be emphasized that, in some cases, these processes occurred simultaneously (e.g. *grappling with self-management* and *trying out self-management strategies*). Additionally, some participants experienced specific processes relating to difficulties with self-management integration: *struggling with self-management* or *avoiding recommended self-management*. Finally, *interpreting self-management* describes two separate over-arching perspectives which participants may adopt once they have recognised the importance of integrating self-management strategies into their daily life.

In relation to the potential sequential process of self-management integration, participants described the initial process of attempting to integrate self-management into daily life as one characterised by difficulty, internal conflict and hard work, where they grappled with suddenly having to engage with self-management behaviours. This is unsurprising given the intense demands of post-treatment consequences that survivors have to manage relatively independently in this period [4]. Indeed, one participant highlighted her difficulties adjusting to the transition away from structured multi-disciplinary support following treatment, simultaneously wanting to return to the hospital for further support and wanting to self-manage at home. HNC survivorship literature has consistently reported that survivors' quality of life deteriorates substantially in the period immediately following primary treatment, and that potential targets for self-management (such as emotional distress and PEG-feeding) have a substantially negative influence on quality of life in this period [26]. The current findings suggest that self-management following primary treatment may involve a lot of hard work on the part of HNC survivors, and many may find it difficult to motivate themselves to integrate practices like PEG-feeding into daily life during this period due to conflicting experiences and feelings towards food. Managing emotional challenges may also be difficult to incorporate into daily life during this period due to frustrations at functional loss and worries that the experience of unusual symptoms and sensations (both experienced and imagined) signify a possible recurrence. Following, or simultaneous to, this grappling process, participants tried out a variety of self-management strategies in order to see how well they fit the specific context of their lives. This involved, for example, testing different foods or products to see if they were suitable, abandoning those self-management strategies that were not suitable to their life context and re-learning how to perform particular behaviours. These findings help clarify a previously unexplained finding in the self-management literature that certain individuals abandon particular self-management behaviours over time [27]; in the current study, participants chose to abandon those self-management strategies that did not help them or "fit" the context of their lives. If survivors were successful in identifying the self-management strategies that fit their life context well, this process of trying out different self-management strategies enabled them to become expert self-managers; they were able to plan for self-management in advance or respond to situational demands and challenges they encountered with a flexible use of different (and sometimes multiple) self-management strategies, depending on what they deemed to be most appropriate for a particular context. The findings that participants adopted flexible and novel strategies for integrating self-management strategies into their daily lives and abandoned self-management strategies that failed to meet their specific needs emphasise how self-management integration is an individualistic process for HNC survivors, and that such individuals appear to purposefully consider their life context

when choosing to adopt or abandon particular self-management strategies. These findings also resonate with the ideas of Paterson et al. [28], who suggested that individuals with long-term conditions typically learn to make decisions about their self-care autonomously at some point, making adjustments to care plans that best suit their bodies or their social context.

Once they recognised the importance of self-management integration, participants also described how they interpreted self-management with regard to the specific context of their lives. These participants interpreted self-management in a way which either prioritised focusing on their recovery or recuperation or prioritised a return to valued roles and responsibilities. In either case, these participants used self-management strategies as a means to assist their prioritisation of recovery or returning to roles and responsibilities within their specific life context. Although this is similar to Auduly and colleagues' [11-12;27] findings that individuals with long-term illnesses negotiate between a "life-oriented" or "illness-oriented" perspective, the current findings serve to further clarify this idea for HNC survivorship by pointing towards a process of interpreting self-management where HNC survivors opt to prioritise one of these aspects of their life and use self-management strategies as a means to facilitate this prioritisation. It is worth noting that several participants indicated that they began to interpret self-management in a recovery-oriented fashion after "being given the all clear" by a health professional. Hornsten and colleagues [14] suggest that at a certain point in the illness trajectory, individuals with long-term illnesses pass a "turning point" where they integrate self-management practices and feel a responsibility to focus on their recovery; the current findings suggest that "being given the all-clear" may represent such a "turning point" in cancer self-management for certain individuals and one which may facilitate a recovery-oriented perspective on self-management. Other individuals interpreted self-management in a manner which prioritised returning to their roles and responsibilities and engaging in work and daily activities. Such findings resonate with other research on self-management of long-term conditions which has found that certain individuals may be reluctant to abandon life goals and everyday priorities in favour of a recovery-oriented interpretation of self-management [11;13;28-29]; in the current study, these participants even described how they often used self-management strategies as a means to re-focus on returning to normal roles and responsibilities. Engaging in work and normal activities also helped such participants to divert their attention from fears of recurrence, perhaps allowing them to experience "flow" or total immersion in a task or activity [e.g. 30]; such experiences have been found to help individuals with cancer to banish intrusive thoughts about their condition in occupational therapy interventions [31]. Future research could investigate the extent to which such "flow" experiences may allow cancer survivors to alleviate fears of recurrence in the post-treatment period.

An additional striking finding in the current study is that several participants struggled to integrate particular self-management behaviours into the context of their life, such as giving up smoking, managing ongoing persistent challenges (e.g. eating behaviours) or living with a changed identity. The HNC survivorship literature has clearly documented how persistent problems such as social eating and fear of recurrence can interfere with global and emotional aspects of quality of life over time [26;32] and how some HNC survivors experience a diminished sense of self over a prolonged period of time which is linked to functional, social and existential losses they encounter from diagnosis to survivorship [33]. The current findings suggest that some individuals who struggle with such persistent issues may require additional ongoing support from health-care professionals, family members, other individuals or services

who may assist in their recovery. These findings also contrast with other literature on the processes of self-management integration in illnesses like diabetes, where participants have described a low impact of illness self-management on their daily lives [14]. This supports the suggestion that there may be a qualitative difference between cancer self-management and the self-management of other long-term conditions, which may not carry the same burden of existential and emotional threat [1;17]. It may also be the case that “struggling to integrate self-management” is a transitional phase that relates to the process of trying out different self-management behaviours. In other words, those HNC survivors who reported that they were struggling to integrate self-management into their lives may have encountered difficulties trying out self-management strategies and had not yet decided to abandon those strategies that were not working for them. It is possible that there is a culmination of experience that occurs between trying out self-management strategies and becoming an expert self-manager which enables HNC survivors to develop the confidence to abandon self-management strategies that do not work for them; this warrants further exploration in longitudinal qualitative research.

Some participants also described their experiences of avoiding recommended self-management strategies and engaging in negative health behaviours, e.g. smoking and abusing alcohol to cope with significant life events, and relieve boredom and stress. Hibbard et al. [34] suggest that people may not be able to adopt or maintain new healthy behaviours when faced with life stress or a health crisis. Furthermore, cognitive dissonance [e.g.35], involving justification of persistence with a damaging behaviour as a result of the tension created between seemingly contradictory beliefs about the behaviour in question, may be influential in the maintenance of unhealthy habits. These findings diverge from similar research by Audulv and colleagues [11-12] who suggest that individuals make rational decisions about whether to take up particular self-management behaviours or not in the context of how threatening a long-term illness is, and what can be done to limit its impact. In contrast, it appears that some cancer survivors may respond in a more emotional manner to negative life events through the use of damaging health behaviours to cope, or they may use cognitive dissonance to justify their continued use of behaviours which have a deleterious effect on their health.

There are a number of implications of the current findings for interventions to support self-management for HNC survivors in the post-treatment period. The findings indicate that HNC survivors may require skills training and structured support in order to assist them in the transition between in-patient care and having to self-manage after primary treatment, and may require further ongoing support in some cases to deal with persistent and recurring challenges such as eating difficulties. In this regard, structured self-management support interventions which maximise individuals’ capacity to build supportive social networks and enabling environments which facilitate self-management practices [e.g. 36] may be particularly important for HNC survivors. Furthermore, the findings relating to individualised approaches to self-management or the abandonment of particular self-management strategies suggest that particular self-management strategies may not be acceptable for, or perceived as helpful by, all HNC survivors as they may not integrate well with their life context. This elucidates a consistent finding in the literature that interventions to support self-management should not be a “one-size fits all” approach [37-40]; rather programmes which are designed to enable HNC survivors to become expert self-managers may need to be tailor-made with particular consideration given to the life contexts of survivors in order for them to be acceptable to them. Furthermore, while orthodox perspectives on self-management typically suggest that individuals



with long-term illnesses are focused on their recovery but differ in their abilities to actively self-manage their condition [41-42], our findings have demonstrated that HNC survivors may prioritise returning to their roles and responsibilities over focusing on promoting their survival and recovering their health and well-being through the use of relevant self-management strategies. Alternatively, HNC survivors may participate in harmful behaviours which they know impact negatively upon their health and well-being but which they deem to be effective ways of coping with negative life events. Self-management support interventions should tailor delivery to account for these findings by being mindful that individuals may have their own priorities which supersede their active participation in recommended self-management behaviours, or which may enable them to self-manage in their own way. Finally, the current study has highlighted the importance of explicitly targeting fear of recurrence in cancer self-management interventions.

This study has a number of strengths and limitations. In particular, the cross-sectional nature of the design meant that participants retrospectively described their attempts to integrate self-management into their daily lives following primary treatment. Individuals may express different concerns and highlight different experiences in a longitudinal study about post-treatment self-management integration as they encounter particular self-management processes in context. Furthermore, the study is limited to describing processes that relate to a specific group of HNC survivors' attempts at integrating self-management into their lives following treatment; other HNC survivors may experience different processes relating to additional challenges, there may be different self-management processes at different stages of the cancer trajectory and individuals with other cancers or long-term illnesses may experience different processes in their self-management integration attempts. Nonetheless, the study clearly distinguishes particular examples of self-management integration processes which involve specific HNC-related issues (e.g. eating difficulties) and those which may affect cancer survivors more generally (e.g. fear of recurrence). Furthermore, the rich and varied experiences of participants demonstrate the credibility of the research and the use of a purposeful critical case sampling method meant that we included a diverse sample of survivors with a range of different post-treatment challenges.

To conclude, this study is the first to describe and characterize HNC survivors' attempts to integrate self-management into their daily lives following primary treatment. A key message from this research is that cancer survivors often learn to engage in highly individualised approaches to self-management depending on the unique context of their lives, and may abandon self-management strategies that fail to meet their specific needs. Nevertheless, they may also need ongoing support to deal with persistent challenges and recurrence fears in the post-treatment period.

### **Compliance with Ethical Standards**

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### **Conflict of interest**

All authors declare that they have no conflict of interest to report.

## Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. We received formal ethical approval for the study from the following institutions in Ireland: Galway University Hospitals (Merlin Park University Hospital Clinical REC\_C.A.1100); South/South West Hospital Group (UCC Clinical REC\_ECM\_4\_(bbb)\_03/06/14); St. James's Hospital, Dublin (SIH/AMNCH REC Reference: 2014/05/Chairman's\_Action), Royal Victoria Eye and Ear Hospital, Dublin (RVEEH REC\_25/06/14).

## Informed consent

Informed consent was obtained from all individual participants included in the study.

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